



In recognition of **NF Awareness Month**, the Children's Tumor Foundation is highlighting exceptional stories from Neurofibromatosis (NF) patients across the country that have participated in, and benefited from, crucial clinical trials of targeted therapies that aim to treat NF and its symptoms. NF is a genetic disorder that affects 1 in 3,000 people of all populations, and causes tumors to grow on nerves throughout the body. It has three distinct forms: NF1, NF2, and schwannomatosis, and can be presented in a number of harmful ways, such as blindness, deafness, learning disabilities, disfigurement, bone abnormalities, disabling pain and cancer. Results from NF research can therefore be applied to other disease areas, and benefit the broader public. The story below reflects both the adversity faced by this NF hero, as well as new hope from promising new treatments.

**NF Hero: Jess Toews**

**Age: 34**

**State of Residence: Kentucky**

**Type of Neurofibromatosis: NF2**

### ***Jess' Story:***

I was diagnosed with NF2 in September 2009 at the age of 27. I was lucky enough to have brain surgery on my 28th birthday to remove a tumor, which also took my hearing on the left side. On March 12, 2015, I had a significant drop in hearing. I am already deaf on the left side and have lost almost all hearing on the right. I am a wife and mother of two kids. I was confident that I could deal with being deaf, but I wasn't happy about it. The thought of never hearing my young kids laugh again was pretty devastating. My husband made an appointment for me at Cincinnati Children's Hospital NF Clinic to see what my options were. We met with Dr. Trent Hummel, who suggested I should try Avastin. At first things were rough. The hospital is two hours away from my home and I had some side effects. As of today, I have been on the Avastin drug therapy for one year. At my last hearing test, I had regained significant hearing with 80% word recognition on my right side. It is a miracle. I can't explain how amazing it is to hear my kids laugh, attend church, and be a pretty normal member of society. I am beyond thankful for the ability to hear. Avastin has given me hope!

**FOR MORE INFORMATION ON NF, PLEASE VISIT [WWW.CTF.ORG](http://WWW.CTF.ORG)**